

# Supporting Doctor Visits

A person with an intellectual and/or developmental disability (IDD) may need support with doctors' visits. It is wise for you, as the service provider, to inform the medical office in advance about communication needs and devices as well as other accommodations that will help the appointment go well. Communication barriers are particularly challenging as you try support self-advocacy. Most doctors try to keep appointments within limited time frames, so it is critical to make the most of this time.



## Making an Appointment

It is a good idea to understand the process for making an appointment and build a relationship with the receptionist. Have the accommodation needs of the person ready to discuss. If waiting in the waiting room is difficult, it may be possible to schedule the first appointment of the day or the first appointment after the doctor's lunch break to minimize time spent in the waiting room. If noisy active spaces are difficult be prepared to ask for a sensory friendly space. If the person has significant challenges, it may be possible to schedule a double appointment.

## If an Accommodation is Needed

It is important to ask for accommodations in advance or when making the appointment. Tell the scheduler or the receptionist what is needed. Try to get accommodation requests included in the persons medical record.



## Preparing for the Appointment

- The person can take a support person if they choose. This person can help them prepare for the appointment.
- To help the person be ready for the visit, explain why (and when) they are going. It is important that the person is clear about the reason for the visit. If they are anxious, provide reassurance.
- Ask in advance what questions they may have for the doctor and write them down.
- It may also help to role-play with them to give them a chance to practice.
- If there is a behavior support plan, share that with the doctor and office staff.
- Have any supported decision making or guardianship information ready if needed.

## Helping the Person Communicate with the Doctor

Some people do not use words, but they have other ways to express themselves. Some people use sign language or pictures. Others may use hand gestures and facial expressions. Others may use a communication device. As a support person you may understand what the person is trying to say and help them understand what the doctor is saying.

### Consider These Steps:

- Encourage the person to see a doctor they are comfortable with. Try to see the same doctor every time.
- Explain to the doctor how the person communicates and how you assist.
- Physician's assistants, nurses and others may be good resources for communication.



### During the Visit

- Ask the doctor to speak directly to the person. If the doctor starts by asking you questions, repeat them to the person for them to answer. Or ask the person if it is OK for you to talk about their health problem with the doctor.
- Encourage the person to ask any questions they would like answered. Start with the ones you wrote down.
- Make sure the person clearly understands all information needed to decide about treatment options.
- You can assist with communication or decisions as needed, while keeping the person's best interests in mind.
- Be prepared with the person's supported decision making information or guardian consent for treatments.
- If a new medication is being prescribed, support the person to ask about side effects or any other questions they have about the medication.
- Ask the doctor to write down instructions in plain language and explain difficult words.
- Ask about any follow-up visits.

### After the Visit

- Check that the person understood what happened and what the doctor said.
- Work with the person to make sure there is a system in place to carry out any instructions they received from the doctor.
- Determine whether other health care professionals need to know what the doctor said.

# Making and Using a Personal Profile Card

The "My Profile" card is a tool you can easily create to help with requesting accommodations.

## What Should a Personal Profile Include?

- Include a picture of the person when they are well.
- Include name, birthdate, and what name they go by (nickname).
- Lists the basic accommodations that will help the appointment go better.
- How the person communicates - for people who do not use many words, describe other ways they communicate, how they show pain and contentment, and how they express yes and no.
- Strategies to help the person stay calm and cooperate with medical procedures.
- Any relevant religious or cultural practices, dietary restrictions or fasting periods, and alternative therapies or herbal supplements.
- The profile can be helpful with many kinds of healthcare visits. It may be good for other occasions too.



## Example of a My Profile Card:

Category	Request
Sound	Speaking to me quietly.
	Giving me a quiet place to wait. Allow me to listen to music on my headphones.
	Talking to me slowly and asking me follow up questions to make sure I understand. I will need extra time to respond.
Sight	Taking off your white coats before meeting with me.
	Keeping the lights low.
Time	Giving me examples of how long the wait will be.
	Minimizing my appointments to less than 5 minutes with the doctor in the room.
Space	Allowing me to nap in my wheelchair until the team is ready to see me.
	Keeping the room door open. I do not like small spaces.
Touch	Not offering me a Band-Aid, I do not like them.
	Asking my permission before touching me.
Reinforcement	Being extra gentle with my hand/leg/other body part. It is extra sensitive.
	Drawing pictures when you are explaining things helps me understand.

Link to My Profile Card:

<https://bit.ly/3V18Qjh>



### Acknowledgement

The Iowa Taking Charge of My Health (TCMH) curriculum, including power points, worksheets and fact sheets is inspired by Oregon's University Center for Excellence in Developmental Disabilities (UCEDD) Taking Charge of my Healthcare Toolkit which can be found at <https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care>.

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The information provided is for general use and not medical advice or intended to address any individual situation.